Best Practice

TOPICS IN REVIEW

Hope in the terminally ill

Hope is the wings upon which the future soars.

ANONYMOUS

INTRODUCTION

The diagnosis of a terminal illness initially precipitates a vulnerability and isolation that belie description as contemplation of one's impending death transcends the mundane activities of daily living. Mortality is suddenly confronted, and the concept of hope wanes as the unattainable goal of extended life vanishes. And while denial may temporarily intervene and preclude reality, the fact that life is ending becomes hard to deny as the disease advances. But a seemingly paradoxic question arises: because hope is frequently defined as the expectancy of good in the future, how can a future defined in hours, days, weeks, and months provide hope?[1] To understand the answer to this contradictory question, physicians must acknowledge the dynamic and complex nature of hope and how it changes during the dying process.

REPORT OF A CASE

Mrs Brown was a 69-year-old widow with metastatic breast cancer and with no known family. Although she had undergone chemotherapy and radiotherapy, the disease progressed relentlessly. Her oncologist proposed another chemotherapy regimen using a new agent with substantial adverse effects. After 3 episodes of the new chemotherapy, Mrs Brown was debilitated, emaciated, depressed, and hopeless. The oncologist suggested a break from treatment for 3 to 4 weeks to allow her nutritional and functional status to improve, after which chemotherapy could be reinstituted.

In the interim, the patient was enrolled in a hospice program. The hospice staff developed rapport with her, assisted her with a life review, discussed the terminal nature of her disease, and discovered that she was estranged from a daughter she had not seen in 30 years. After diligent labor, the hospice social worker located the daughter and arranged for a meeting at the patient's home. Mrs Brown's spirit improved; she was excited about the impending visit with her daughter and elected not to proceed with chemotherapy, considering the extent of her disease and the adverse effects of the treatment. The false hope of a relatively futile medical intervention (chemotherapy) was replaced with an appropriate and humane hope of reconciling with a long-lost daughter, resolving familial discord, and experiencing an improved quality of life.

Paul Rousseau
Geriatrics and Extended Care
Veterans Affairs Medical Center
Phoenix, AZ 85012

Correspondence to:
Dr Rousseau
PalliativeDoctor@aol.com

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Sam Tanner/Photofusion

Encouraging lightheartedness and humor, when appropriate, can engender hope in terminally ill patients

Interventions that engender hope[1,8]

- Adequate control of symptoms
- Fostering and developing interpersonal connectedness and relationships
- Assistance in attaining practical goals
- Exploring spiritual beliefs
- Supporting and identifying personal attributes, such as determination, courage, and serenity
- Encouraging lightheartedness when appropriate
- Affirming worth by treating the patient as a valued individual
- Recalling uplifting memories with life review

THE MEANING OF HOPE

Unfortunately, physicians often consider hope and terminal illness mutually exclusive. Many equate hope with cure in the archetypal disease-illness paradigm and may express this notion to patients.[2-4] As Nekolaichuk and Bruera note, people who are terminally ill often become marginalized from mainstream society.[2] This marginalization is associated with existential distress, social isolation, and loss of familial and occupational roles, which can further dissipate hope.

When first confronted with a terminal illness, most patients typically relate hope to a tangible treatment or cure that can prolong existence despite overwhelming information to the contrary. Part of this illogical hope may derive from inappropriate information given by physicians to patients when delivering bad news. Physicians are characteristically hesitant to deliver devastating news and may abstain from truth telling in an effort to sustain and bolster hope. They frequently temper the diagnosis of a terminal illness with unrealistic and unintentional "therapeutic" hope. Such misguided hope may involve telling patients about futile treatments such as chemotherapy, radiotherapy, and surgery, which can create false expectations. It may also help physicians to deal with their feelings of impotency in the face of a relentless disease and certain death.[3] As Brody noted, however, an accurate disclosure of the truth can almost always be coupled with an element of hope.[5] Physicians are persuasive modulators of patients' hope.[6] Practitioners who care for patients with terminal and life-threatening disease face the challenge of balancing honest communication with maintaining hope.[7]

After patients' initial anguish at the news of their terminal illness, the future often becomes defined by family, close friends, and the meaning attached to life, rather than to the length of time remaining. Patients' thoughts and concerns become more global as they envisage, and hope for, a positive outcome for their family and friends. Then, as death approaches, patients often focus on themselves, expressing a desire for serenity, inner peace, and eternal rest.[1]

DETERRENTS TO HOPE

Unfortunately, deterrents to hope may exacerbate the fear and trepidation surrounding dying and preclude a peaceful and tranquil death. In a study by Herth, 3 obstacles hindered hope: abandonment and isolation, uncontrolled pain, and devaluation of personhood.[1] Herth identified 4 sources of hope, including family, friends, health care professionals, and God or a higher spiritual being. Because health care professionals are a source of hope, they must remember that specific strategies foster and maintain hope in their patients. Aside from compassionate disclosure of the diagnosis of a terminal illness, physicians can engender hope through various mechanisms (see box). Life review, in which patients recount their lives, jobs, travels, and experiences, is a simple and important intervention to help patients achieve purpose and meaning at the end of life. Nuland proposes that hope resides in the meaning of what our lives have been.[3]

CONCLUSION

Hope is the expectancy of good in the future. It plays a role in the successful coping with illness and in improving the quality of a person's life. In the context of a terminal illness, hope can exist even when time is limited. Such hope is bolstered by appreciating our patients' value, strengthening and reconciling their relationships with family and friends, helping them to explore spiritual matters, and controlling their symptoms. Although physicians may find it hard to comprehend, when everything seems to be lost, that hope may actually be stronger than ever before.

Dr Rousseau is the Medical Director of RTA Hospice, Phoenix; Adjunct Professor of Adult Development and Aging, Arizona State University, Tempe; and a member of the Adjunct Clinical Faculty, Arizona College of Osteopathic Medicine, Glendale, AZ.

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